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ABSTRACT

Caring for a family member with dementia is a major source of stress for the caregiver. To assess the impact of caring for an impaired family member and to evaluate the effectiveness of intervention programs, 34 caregivers of relatives with dementia completed an amended form of the Philadelphia Geriatric Center's Caregiver Survey and two psychosocial measures assessing depression and social mastery. The Caregiver Survey assessed family history, the impaired person's problems, caregiving, social support, caregiver characteristics, and caregiver goals. Results of the survey indicated that the key factor affecting level of caregiver depression was the level of cognitive impairment in the care receiver. Depressed caregivers were characterized as being socially isolated and unassertive while nondepressed caregivers were more likely to be employed, to have paid help, and to participate in support groups. Although high social mastery caregivers were more likely to report being able to assess the care receiver's needs, handle caregiving problems, and participate in other activities, they were also more likely to be caring for a distant relative rather than a parent or spouse. These results suggest that caring for an impaired close relative clearly increases one's feelings of stress and burden and decreases one's feelings of mastery. These findings further suggest that intervention strategies should involve aggressive case management, counseling, and supportive therapy. (BL)

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CAREGIVING FOR DEMENTIA IN FAMILY MEMBERS: CAREGIVING BURDEN AND PROSPECTS FOR EFFECTIVE INTERVENTION. Robert J. Maiden, Alfred Univ., Patricia Maiden, Allegany Rehabilitation Assoc., Alan Keohane, Allegany County Office for the Aging.

The purpose of this research was to provide data for effective intervention in caring for dementia. An amended form of the Philadelphia Geriatric Center's Caregiver Survey was administered to 34 caregivers. Results indicated adjustment reflected relatedness of carereceiver, availability of a social support network, counseling, and use of in-home services. An intervention strategy was discussed suggesting a more aggressive case management program and more utilization of psychological counseling and supportive therapy.

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CARING FOR DEMENTIA RELATIVES: CAREGIVING BURDEN AND PROSPECTS FOR EFFECTIVE INTERVENTION

We are currently witnessing a period of great change in family relations especially between generations. For instance, we are witnessing the emergence of the four generational family. In these families, the children of the oldest generation are themselves elderly and often have obligations to their aged parents, spouse, siblings, or in-laws as well as obligations to their children and grandchildren. This multiplication of family demands places tremendous stress on these individuals in the "sandwiched generation."

A major source of stress of the "sandwiched generation" is caring for a parent, spouse, sibling, or in-law with dementia. Approximately 5 to 10 percent of the population over the age of 65 has dementia. The likelihood of dementia increases with age so that by the age of 80 up to 20 percent or more suffers from this disease. Two and one half million Americans now suffer dementia. Dementia means loss of reason and is a disease that attacks the brain and causes severe memory impairment and cognitive and intellectual decline. Dementia is a disease with no known prevention, treatment or cure. (Fischman, 1984). A still larger number of Americans suffer from the effects of this degenerative disease in a relative or loved one.

Although the majority of families prefer to keep their relatives out of institutions as long as possible (Brody, 1974), the impact of dementia drains the families' physical, emotional, and financial resources (Isaacs, 1971; Lowther & Williams, 1966).

Oftentimes, the stress of caring for a cognitively impaired relative results in a physical disorder (e.g., hypertension and heart attacks) and psychiatric disorders (e.g., depression, alcohol and substance abuse), as well as maladaptive behaviors reducing family members to patients themselves (Eisendorfer & Cohen, 1981). Caregiving has been found to be harmful to homemaking, recreational, and vocational activities of the caregivers (Steuer & Clark, 1982). Furthermore the caregiver may react to the patient's cognitive impairment by fostering dependence through over-solicitiousness and/or lack of knowledge (Kuypers & Bengston, 1973). This may result in the caregiver increasing his/her own feelings of burden, as well as creating excessive disability to the parent. Despite these areas of family conflict most experts conclude that it is primarily the family that is most important in providing adequate care for the impaired family member. To quote Carl Eisendorfer (1983), "When the family goes, the patient goes."

Currently, most interventions for families caring for a relative with dementia have been designed on intuitive beliefs about what will help the caregiver. To more clearly specify the impact of caregiving on an impaired family member is a key goal of this study to better evaluate the effectiveness of intervention programs. In our analysis, depressed caregivers are compared to nondepressed caregivers who felt in control of their lives. The differences between these two types of caregivers suggest who are most vulnerable to feelings of stress and burden and where we may turn to do something about it.

## METHOD

### SUBJECTS

The participating families were identified by their local area Office on Aging or by a friend. Thirty-four caregivers agreed to volunteer for this project. They resided in a three county area (Allegany, Steuben, and Chautauqua Counties) with the largest proportion residing in Allegany County. The key qualification was that the participant was caring for an impaired family member in their home. Not all of the carereceivers were diagnosed as having Alzheimer's disease, but virtually all of them were experiencing cognitive deficits.

### PROCEDURE

A graduate or undergraduate research assistant interviewed the caregiver after contacting him/her by phone and making an appointment for an interview. The interview while extensive only took about 45 minutes to complete. The caregivers' responses were recorded by the research assistant. The interview itself tapped a wide range of areas such as family history, problems of the impaired elderly person, information about the caregiving, the caregiver's social support system, characteristics of the caregiver, the goals of the caregiver, and two psycho-social measures of the caregiver's emotional functioning. These psycho-social measures tapped depression (The Geriatric Depression Scale) and personal and social control over the environment (The Social Mastery Scale). The Caregiver Survey instrument was designed by the Philadelphia Geriatric Center with the exception of the latter two measures of psychological functioning.

## RESULTS

First, let us analyze the demographic and descriptive data and how they impacted the caregivers' feelings of social control and mastery.

The demographic data showed us that the average age of the caregiver was 53 and the average age of the carereceiver was 82, so that the young-old, if you will, were taking care of the old-old. Three out of four of the caregivers and carereceivers were women. Virtually all were white (94%), predominantly Protestant (59%), highly educated (an average of 14 years of education for the caregiver, and 12 years for the carereceiver) and relatively affluent (11 out of 26 reported incomes of $1400 and above per month). Most caregivers were employed (20 out of 30 reported this) with approximately half of them working part-time.

The medical history of the carereceiver revealed that the first change in cognitive functioning occurred on average about 10 years prior to the study. The first sign was generally a medical problem and the onset in most cases was gradual and degenerative (85%). Nevertheless, physicians only infrequently recommended institutionalization (27% of the cases). Examining the caregiver's descriptive feelings of stress and burden, we discover that one in three reported feeling tired, upset, isolated and resentful. Over half of them felt depressed (56%) and were afraid of what the future held for them and their impaired family member (57%). Slightly over half of the caregivers suffered insomnia. Nine of twenty-nine reported participation in a support group or individual counseling.

Looking at emotional level, we discovered the key factor affecting level of depression was the level of cognitive impairment

in the carereceiver. The poorer the level of functioning of the impaired family member, the more likely the caregiver was depressed. The impaired family member of a depressed caregiver was more likely to be suffering from atherosclerosis (.57 $p < .001$), to be overly restless (.42 $p < .007$), and to be unable to prepare meals (.26 $p < .07$). Also, the more sudden the onset, the more likely the caregiver felt depressed. Not surprisingly, depression was also significantly correlated with not having enough money to care for the impaired family member in addition to the rest of the family expenses (.52 $p < .001$).

The burden of caring for an impaired relative deleteriously impacted the depressed caregivers' state of health. They were more likely to report being distressed by dizziness (.28 $p < .05$), weaknesses in parts of their bodies (.38 $p < .01$), feeling easily annoyed or irritated (.54 $p < .001$), and nausea or upset stomach (.30 $p < .04$). Moreover, they stated that their health was not as good as it was three years ago (.41 $p < .009$), and that their health problems stood in the way of them doing the things they wanted to do (.38 $p < .01$). Further analysis indicated that the depressed caregiver was isolated socially (.29 $p < .05$), was not engaged in social activities (.32 $p < .03$), and was unassertive (.39 $p < .01$). A significant percentage of the depressed caregivers (.33 $p < .03$) felt that they were living up to their religious principles in taking care of their impaired family member rather than providing a good model for their children to follow or in being true to family traditions.

Looking at nondepressed caregivers we find they were more likely to be employed (.31 $p < .04$), to have paid help coming into

their home (.35 $p < .02$), or to have available a place outside the home to take care of their impaired family member such as day care, respite care, and so on. (.34 $p < .03$). Also, the nondepressed caregivers were more likely to participate in a support group or have individual counseling (.31 $p < .04$) and were still capable of feeling particularly excited or interested in something (.25 $p < .07$).

Compared to the depressed and nondepressed caregivers, high social mastery caregivers were more likely to feel that they could figure out what their impaired family member's needs were (.38 $p < .01$), that they could handle most problems in the care of them (.30 $p < .04$), and that they could fit in most of the things they needed to do in spite of the time taken in the care of their relative (.43 $p < .007$). High social mastery caregivers were less likely to feel that they needed help in caring for their impaired family member (.32 $p < .03$). Yet they were more likely to employ outside professionals to help them out (.34 $p < .03$). Moreover, they were more likely to be employed (.30 $p < .04$), and less likely to have participated in a support group or individual counseling (.33 $p < .03$).

Perhaps a very revealing finding was that the high mastery caregivers were caring for a less impaired family member who needed little assistance yet they were more bothered by their relative's behavior and problems. For example, they were embarrassed by their impaired family member (.40 $p < .009$), and they found incontinence more troublesome (.31 $p < .05$).

The above findings suggest that high mastery caregivers are less willing to care for a seriously impaired person who is also a

family member. This impression may be further supported by the finding that high social mastery caregivers were most likely to be caring for a distant relative such as an in-law rather than a spouse or parent (.56 $p < .0001$). This finding was the most statistically significant correlation in the entire analysis. Of course, the problem with correlational research is that it does not reveal causation. We are left with an interesting question. Does caring for an impaired family member who is a close relative result in feelings of no control, one's personality structure notwithstanding? In other words, are situation factors more important than personality traits here? Whatever the true answer to the above question is, it did appear in this study that caring for an impaired family member who is a close relative clearly increased one's feelings of stress and burden and decreased one's feelings of mastery and control.

IMPLICATIONS

Two implications may be drawn from our analysis: one for counseling and one for allocation of resources. Our analysis revealed that the most vulnerable group of caregivers were those who were caring for an impaired family member who was a close relative and that they were often strained beyond their financial resources and were socially isolated. This paper found the solution was to strengthen one's social support network, through support groups, family (psychological) counseling, or social visits. A similar solution has been proposed by other authors such as Zarit (1980) who found that even social visits from another family member, or even by an in-home service aide, significantly relieved feelings of overwhelming stress and burden in the caregiver. The key to better

mental stability and emotional well-being is simply for the over-burdened caregivers to experience more social involvement and more outside help. The fact that this study found counseling to help relieve the caregiver's feelings of burden, I believe, was very important as so few studies show the positive impact of psychological intervention can have with these families - as mental health is one of the most underresearched, underfunded, and overlooked areas in gerontological services today.

The second implication involves providing the caregiver with information and consultation regarding alternative services and their cost. In short, the need clearly is for an aggressive consultation service that matches caregivers to available services. I emphasize aggressive because as you recall our analysis revealed that the depressed caregivers (about half of our subjects) were less likely to be assertive or participate in an activity and they were more likely to be socially isolated and alone. Fortunately, such programs are on the horizon and are becoming more visible. Clearly our own analysis shows that caring for a spouse or parent with Alzheimer's disease is more than any one person can handle alone.

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